

## How nurses' attitudes and actions can influence shared care

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# HOW NURSES' ATTITUDES AND ACTIONS CAN INFLUENCE SHARED CARE

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## SUMMARY

**Background:** Patients with long-term conditions may benefit from involvement in decision-making and the management of their condition. This requires nurses to have a training role, which may conflict with their traditional identity as nurses.

**Aim:** To explore the differences in attitudes and behaviours of 'carer' and 'trainer' nurses to patients taking increasing responsibility and control of their own care on long-term haemodialysis wards.

**Design:** Qualitative comparison of different nursing styles.

**Methods:** Semi-structured interviews were undertaken with 30 patients and 44 nurses between September and November 2012. Participants were recruited from seven haemodialysis units in the UK. Data were analysed thematically using codes derived from theories associated with the research questions.

**Findings:** 'Carer' nurses give bite-sized chunks of information to their patients about diet and medication. Treatment decisions are made with minimal patient discussion and all aspects of dialysis are performed by staff. Nurses who are most like trainers encourage patients to have a broader understanding of their condition and genuinely involve patients in decisions. Such nurses are happy to encourage appropriate patients to self-dialyse.

**Conclusion:** Initiatives to enable patients with chronic illnesses to look after themselves have the potential to empower patients, aid recovery and save money. However, such initiatives can create tension between the carer identity of nurses and their role as trainers. To encourage haemodialysis patients to dialyse themselves, nurses need to: educate for broad understanding and empowerment; participate in patient-led decision-making about diet and lifestyle; and encourage shared decision-making for medication and dialysis.

**KEY WORDS** Haemodialysis • Nursing • Patient involvement • Self-management/self-care

## INTRODUCTION

Enabling patients to be more involved in their own treatment can empower patients, aid their recovery and save money (de

Silva 2011). This paper explores the 'carer' and 'trainer' attitudes and actions of nurses on long-term renal dialysis wards in order to elucidate aspects, which promote patient involvement.

## BIO DATA

**Ian Davison**, BA, PGCE, PhD, is a lecturer at the University of Birmingham, where he leads the Education for Health Professionals' Masters programme. For the last 10 years he has been involved in educational research concerning doctors, nurses, dentists and pharmacists.



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In the UK, in response to health and social imperatives and potential economic benefits, there is currently a major drive to increase patient involvement (Department of Health 2010). This has led to considerable effort to increase the proportion of patients on long-term haemodialysis who dialyse at home rather than in dialysis centres because home haemodialysis is thought to be more clinically effective and cheaper (Ananthapavan *et al.* 2010, NHS Kidney Care 2010). Following this initiative, it has been recognised that for many patients, encouraging them to be involved in their care while dialysing in-centre is an important step towards home haemodialysis: this has been called 'shared care' (Barnes *et al.* 2013).

This study explores how nurses enable patients undertaking long-term in-centre haemodialysis to take increasing responsibility and control of their own care. Our focus is on the nurses' attitudes and actions that may impact upon their engagement with shared care for patients who are not planning to dialyse at home. This is because our previous work indicated that there

was almost universal agreement in the study sites that patients should dialyse at home if suitable, but not that shared care was desirable in itself (Beavan *et al.* 2011). We briefly review relevant literature before encapsulating key ideas.

The term 'shared care' encompasses the idea that patients and nurses work in partnership to address care needs rather than nurses taking a paternalistic role in telling the patient what is best for them (Johansson 2013). Benefits of shared care include improvements in health (Barnes *et al.* 2013), quality of life (Noble *et al.* 2007) and efficiency (Coulter & Ellins 2007); there are also ethical imperatives to greater patient involvement in both care and decision-making (Moss 2011). Patients also report the benefits of dialogue that allows a broader consideration of needs than clinical progress alone (Hope 2013).

Jacelon *et al.* (2011) suggest nurses may act as advocates for patients and their families, offering decision-making and information according to the situation. Yet evidence from earlier studies suggests that nurses tend to focus on technical aspects of care because these are most easily addressed and reinforce the specialist knowledge required (Noble *et al.* 2007). Further, they often use technical targets for patients (such as blood levels) that give an 'illusion of empowerment' (Bennett 2011, p. 154) without actually shifting the locus of power from clinician to patient. Indeed, it has been suggested that dialysis nurses have become 'technologically enframed' (Tranter *et al.* 2009, p. 39) and thus focus on technical aspects of care.

Shared care for dialysis involves nurses training patients to undertake some or all of their dialysis themselves. This requires a cultural change from patient dependency to (partial) independence, enabling patients to have greater control of their condition and be more independent, reducing the need for nursing care (Tibbles *et al.* 2009). Education is vital here but needs to address emotional and cognitive factors as well as behaviours (Onbe *et al.* 2013). In addition, the nature of long-term haemodialysis treatment creates a more stable 'natural-type friendship' (Brown *et al.* 2013, p. 253) between nurse and patient that changes the usual nurse: patient dynamic.

From this brief review, it is apparent that for patients to dialyse themselves and take increasing responsibility for managing their condition, nurses are required to act very differently from those on acute wards. We conceptualise this as a difference between the nurses as 'carers' of passive patients and the nurses as

'trainers' working with active service users. For more capable patients in traditional units, given the right education, expectations and organisation, it may be possible for them to become active service users. It is recognised that shared care may vary according to stage and severity of condition and circumstances of the patient (Johansson 2013) and nurses need to be able to adapt accordingly. It is entirely appropriate for nurses to act as 'carers' for many people on dialysis, especially the most seriously ill. However, we are interested in whether nurses embrace the different attitudes and actions required to train active service users to become independent. Of course the difference between 'carer' and 'trainer' is not absolute; there is a continuum from complete nursing care through different levels of shared care to complete self-care.

## AIMS

Our aim was to explore nurses' attitudes and actions that influence progress towards shared care for patients in long-term dialysis centres. We focused on their attitudes and actions in educating patients and in decision-making as reported by both nurses and patients. Attitudes can be explicit or implicit, and viewed as consisting of emotional and belief components (Katz 1960); here we are using 'attitude' broadly to include instances where one of these components is weak or absent.

This aim developed from exploratory meetings with six renal centres during previous work which indicated that few units were successfully encouraging patients to dialyse themselves in-centre except as a stepping stone towards home haemodialysis (Beavan *et al.* 2011). In the absence of obvious demographic or social explanations, our initial theoretical explanation was that success with a shared care approach was uncommon because it requires a change of emphasis in nurses' attitudes and actions from caring to training.

## DESIGN

This qualitative study was designed to elicit perceptions of different attitudes and actions of nursing staff and their contribution to shared care. Interviews were semi-structured to explore interviewees' perceptions in depth and covered the nursing role, patient education and understandings of patient-centred care: the interview schedules are available in the project report (Davison *et al.* 2013).

Drawing upon previous work and literature, we analysed the data using a form of analytic induction (Hammersley 2010), that

is, we were primarily testing theory, exploring specific questions and using explicit coding strategies to interrogate the data. Once the data and initial (first level) codes were uploaded into NVIVO 10, we analysed the data within this framework using a broadly thematic coding approach (Robson 2011, p. 467). As we explored the data more carefully, these codes were subsequently refined, using an approach that Miles and Huberman (1994) describe as first- and second-level coding. 'Nursing roles', 'patient education' and 'clinical decision-making' are examples of first-level codes; second-level codes included 'attitudes to patient involvement', 'attitudes to shared care', 'actions in educating' and 'actions in decision-making'. A further stage in the analysis was to identify each attitude and action as an example of a nurse as 'carer' or 'trainer'. Coding was reviewed by both researchers to enhance consistency and repeated iterations of the data analysis were checked and referenced back to the original transcripts to reinforce our confidence in the findings.

## **PARTICIPANTS**

Interviews with patients, nurses and nurse managers were undertaken in three hospital and four satellite units across two hospital trusts in (West Midlands, UK) between September and November 2012. Some patient interviews included input from partners. To obtain a broad range of views, all qualified nurses available on each visit were asked to take part, and one nurse declined the invitation. The only criteria for patient interviewees were capability to take part in a telephone interview and having spent a minimum of six months on dialysis. A member of staff in each centre, independent of the researchers, asked patients meeting these criteria whether they would like to participate; the acceptance rate therefore is unknown. All nurse interviews were conducted in the workplace during normal working hours, in quiet side rooms. Patients were interviewed by telephone at times chosen by them, on non-dialysis days unless they requested otherwise. All interviews were recorded once suitable permissions were given, then transcribed, anonymised and returned to participants for checking. Few alterations were made by interviewees, but the process helped to reassure us of the accuracy of the data. On average, interviews lasted about 25 minutes.

## **ETHICAL CONSIDERATIONS**

The key ethical considerations were genuine informed consent and for the interviews to be confidential to the researchers. Before an interview was arranged, potential interviewees were

given a participant information sheet describing the interview's nature and purpose. If the interviewee wished to proceed, a consent form was signed by both participant and researcher. Ethical approval for the project was obtained from the UK National Research Ethics Service (NRES) and Research Governance approval from both hospital trusts. Data were aggregated to minimise identification of participants and centres; likely differences between centres were not investigated for the same reason. Therefore, quotes identify participants as either patient or nurse without indicating the centre, for example, P2 is the second patient, N5 the fifth nurse.

## **FINDINGS**

A total of 73 interviews were undertaken with 30 patients, 6 nurse managers and 38 staff nurses. In all, 83% of nurse managers, 87% nurses and 33% of patients were female. To put patients at their ease, they were asked to say a little about themselves and their illnesses; of the 21 (70%) who volunteered their age, the median was 62 years.

We were interested in whether nurses' attitudes and actions encouraged patients to dialyse for themselves and identified four main areas: patient education and understanding of their condition; decision-making for medication and dialysis; decision-making regarding diet and lifestyle and patient involvement in dialysis. For each area, we considered the difference between 'trainer' and 'carer' attitudes and actions, and whether they have positive effects on progress towards self-care. These four areas are considered in turn and then combined to contrast the attitudes and actions of 'carer' and 'trainer' nurses.

## **PATIENT EDUCATION AND UNDERSTANDING OF THEIR CONDITION**

Understanding of diet, fluid intake, medication and monitoring of the condition (e.g. bloods) is crucial for those on dialysis, so it is not surprising that these were reported to be key areas of education, at least for new patients. The patients were usually shown their monthly blood reports, which were then discussed with them by their named nurses.

Both nurses and patients described short, informal, opportunistic education based around practical treatment issues while patients were put onto and taken off dialysis machines. There were very few instances of taking time to discuss treatment options or to address broader understandings of chronic kidney disease. Many nurses only described telling patients the correct

approach to specific technical matters, which we interpret as an attitude that patients are passive recipients of such bite-sized pieces of information.

Nurses frequently displayed attitudes in which areas of knowledge were seen as 'specialist' held by doctors, dieticians and link nurses for areas including palliative care, transplantation and infection control. Therefore, some nurses' actions were simply to signpost patients in the appropriate direction, strengthening the hierarchical view of expertise with patients being passive recipients of decisions. Many patients were quite happy for information to be disseminated in this way.

As far as diet's concerned, it's mainly done by the dietician... we'll make sure the medications are up to date and if there's any problems we'll talk to the doctor (N14)

The nurses only really know the basic things it seems and... say 'best to ask the doctor about that' (P4)

However, other nurses demonstrated attitudes that were more sensitive to patients who wanted to understand more about their condition and their current emotional state. Some patients appreciated this even if they sometimes felt nurses were 'nagging' them.

Some patients want to know quite a bit about their treatment and conditions and you'll find that they're quite knowledgeable, they'll have researched a lot themselves; and other people, they don't really want to know anything (N1)

My main nurse... she'll give me the results on my bloods and my phosphates will be high, she will question my diet... You know as if they're moaning, they're not, but they're just there to help us at the end of the day (P6)

Many descriptions indicated 'nurse as carer' attitudes. For these 'carer' nurses, education was usually seen as dissemination of information to passive patients; they also demonstrated very hierarchical attitudes and actions, stressing role demarcations and signposting patients to specialists rather than educating patients themselves.

#### DECISION-MAKING FOR MEDICATION AND DIALYSIS

Regarding medication and dialysis decisions, there was very little reported patient involvement unless they were training to dialyse

themselves, which suggests that nurses' attitudes and actions were usually clinician-centred. Many patients were happy with this approach; however, some wanted nurses with more patient-centred attitudes, such as P9, below, who claimed to be more aware of how his dry weight changes than his nurse.

I leave it to them because they're the experts (P7)

My [dry] weight needs to go up. I was told to wait until the weekend, but that's not a good idea. And by last Friday I had crashed so I know that my [dry] weight has to go up (P9)

#### DECISION-MAKING REGARDING DIET AND LIFESTYLE

Here, again, most nurses displayed clinician-led attitudes. They perceived that most patients know what they should do, but need constant reminding and find it difficult to adhere to the stringent demands of their condition.

You do get to know the patients that are compliant. I mean some people have an off day and they will admit that 'oh I was a bit naughty this week' (N2)

What we normally experience is, like I said, non-compliance issue in terms of the fluid intake; that is the normal one; non-compliance in terms of the tablets (N3)

Patients varied in how much they agreed with this attitude. Many had learnt how their body behaves and simply ignored the nurses' instructions, such as a patient who ate bacon and eggs every day without apparent ill effects, but did not tell the staff as he knew he was not supposed to eat them.

Some nurses had more patient-centred attitudes, saying that many patients were aware of how their behaviour affects their bloods and fluid retention. They recognised the benefits of patients taking ownership of decisions and described the decision-making process as one of negotiation in which patients have some control over their condition. However, this was often framed in pragmatic terms.

We sort of encourage the patients to take some ownership of their medical health needs, because otherwise you're just fighting a losing battle (N2)

They know about their body more than us actually. We are here to give them more like advice: as a medical professional

this is not right, but when they go out of the building they know what's going on with their own body (N4)

#### PATIENT INVOLVEMENT IN DIALYSIS

The dominant activity was for nurses to care for their patients, and many patients were happy to leave everything to the nurses. Lack of time, shift patterns and other (more needy) patients were all cited as reasons for nurses acting as pure 'carers'. However, some patients were clearly open to the idea of being more involved and several nurses demonstrated 'trainer' attitudes as they felt patients would participate in shared care if asked.

We're never asked to needle ourselves... I think I'd be able to do it (P3)

I haven't encountered anyone that doesn't want to be involved as well... if you ask them, they're willing to help (N9)

Although the norm was for patients not to undertake an active role in their treatment (unless training to dialyse at home), several nurses and some patients were aware of substantial benefits including greater patient confidence and understanding of the need for fluid and dietary control, which in turn may lead to improved health and reduced readmissions. The important attitude seemed to be about patient ownership of their condition, that is, patients who understand what is happening, are more likely to take an interest in and understand the importance of protecting their own, often frail, health.

The more the patient takes ownership, the more likely to have less admissions and I think the mortality rate is lower (N2)

You're not just teaching them the machine, you're teaching them the mentality of, you know, going about fluid restriction, dry weight (N8)

Just writing it [your own blood pressure] down in the book, you know, it sort of makes you more aware of what's happening (P2)

Although a minority of nurses mentioned the threat posed to their job, the main reason for not actively seeking patient involvement was linked to their role as carer. Having been trained to regard their role as caring for patients, for some nurses, caring seemed to have become synonymous with doing everything for the patient. There was a tension between having a

caring attitude for patients and the benefits of training them to be more independent.

I'm the sort of nurse who mollicoddles my patients really! So it is quite hard for me. But I suppose if you're a bit more proactive and think well you could do that yourself and a bit more pushy then, you know, perhaps they would do more for themselves... it's up to us, isn't it, to change the culture, the nurses to change the culture (N6)

Several nurses clearly felt they should actively encourage more patients to engage in shared care but believed this to be a difficult cultural shift that was much easier with new patients.

It makes me feel uncomfortable thinking about minimal care [i.e. shared care]; yes we should be promoting it more... There's a conflict within us as I do want patients to look after themselves, but also want to care for them (N7)

[with existing patients] 'I think because they've had it done for so long that it goes against their grain and I think the best way to tackle this is when they come in to get them to ... start from the word go' (N13)

The majority of dialysis for patients not training for home haemodialysis was undertaken almost exclusively by nursing staff. Many nurses and patients were happy with nurses acting as carers in this way.

#### THE ATTITUDES AND ACTIONS OF 'CARER' AND 'TRAINER' NURSES

The analyses above suggest the differences between 'carer' and 'trainer' nurses include education and decision-making as well as the actual dialysis. To highlight these differences in attitudes and actions, we sketch portraits of 'carer' and 'trainer' nurses, whilst recognising that most nurses will be somewhere between these two extremes.

'Carer' nurses see their role as caring for ill patients to the best of their ability. They give bite-sized chunks of information to patients about diet and medication but pass on requests for deeper education to others, such as the dietician, doctor or access nurse. Their attitude is that dialysis and medication decisions are clinical; this is shown in their actions as they have minimal discussion with their patients who they regard as

passively needing care. Their instinct is to perform all aspects of dialysis. From the interviews with patients, nurses and nurse managers, this portrait of nurses as carers is an accurate description of the attitudes and actions of many nurses much of the time.

Much of this carer portrait remains appropriate because people on dialysis continue to have serious, long-term illnesses. Therefore, a portrait of a nurse as a pure 'trainer' was not evident and would be unrealistic. However, dependent on the patient's attitude, mood and understanding of their condition, a 'trainer' nurse's approach to education ranges from giving the patient bite-sized pieces of information to encouraging broader understanding of the disease and discussion of life-style. Patients are involved as much as possible in treatment decisions, particularly regarding the fluid to be taken off; decisions are often a compromise achieved by negotiation with the patient. This nurse would be happy to embrace a shared care approach and would gently encourage patients to undertake as much of their dialysis as they can. Table 1 summarises these differences between 'carer' and 'trainer' nurses.

This 'trainer' portrait is perhaps an unattainable ideal, as it is impossible to always gauge the right balance between training and caring for each individual patient. However, our analysis suggests that the nurses in this study more often lean towards caring than training.

A few nurses and managers viewed a patient's understanding of their condition, self-management and self-dialysis as mutually reinforcing. For example, learning how to operate the dialysis machine requires understanding of dry weight etc. and encourages sensible fluid intake.

## DISCUSSION

To encourage patients to dialyse for themselves, this paper has highlighted three areas in which 'trainer' attitudes and actions

are required in addition to the actual dialysis: education for broad understanding and empowerment; patient-led decision-making regarding diet and lifestyle; and shared decision-making for medication and dialysis.

As here, it has been reported that education concerning practical tasks was incorporated into the dialysis routine but staff rarely found time to educate patients broadly (Tibbles *et al.* 2009). It is true that some dialysis patients wish to be passive recipients of care (Bonner & Lloyd 2012), but it is important for nurses to help appropriate patients understand their condition more deeply. Dainton and Wilkie (2013) found that many staff did not want patients to be more actively involved as they were not confident teaching them and worried that patients would make too many mistakes and fail to manage their condition effectively. Our analysis suggests that staff reluctance to engage with shared care goes much deeper than this as it conflicts with their 'carer' attitudes.

Some 'carer' nurses talked in terms of 'compliance'; we disagree with this language and the underlying attitude that it indicates. Rather, we concur with Butterworth (2008) about the importance of respecting patients' autonomy and that a patient-centred approach to decision-making is likely to be more effective.

Our analysis indicates that to increase the uptake of shared care, patient education and decision-making are as important as the actual dialysis. This may explain some of the difficulties in maintaining shared care cultures (Tibbles *et al.* 2009, Barnes *et al.* 2013, Dainton & Wilkie 2013).

## Limitations

The findings are based upon our interpretation of interviews with nurses and patients. We recognise that others may place a different interpretation on the data and that nurses and patients may have given a particular or partial response to our questions.

	Nurse as carer	Nurse as trainer
Knowledge given to patients	Bite-sized chunks of information. Refer to experts	Education for broad understanding
Decisions: diet and fluid	Staff decide	Patient decides given staff advice
Decisions: medical and dialysis	Staff decide	Shared decision-making
Undertaking dialysis	Staff	Patient as much as they are able and willing
Perceived links between patients' knowledge, decision-making and dialysis	None	Seen as mutually reinforcing

Table 1: 'Carer' and 'trainer' attitudes and actions.

Our framework for analysis does not exclude the possibility that there are other areas of importance.

The patients interviewed were slightly younger (median 62 years) than the UK median of 66 for people receiving haemodialysis (Shaw *et al.* 2013) and therefore may have had slightly greater capacity to engage in shared care than the haemodialysis population.

The seven dialysis units in this study were all training patients suitable to dialyse at home, but little shared or self-care was happening for other patients. Therefore, it is not known how the attitudes and actions described here would vary with different amounts of shared care.

### Implications for Practice

We agree with the 'trainer' nurses in our study who viewed the components of Table 1 as mutually reinforcing, a view consistent with findings from an extensive review of many clinical conditions showing that 'health literacy is central' and 'shared decision-making and self-management are mutually supportive approaches' (Coulter & Ellins 2007, p. 27). Therefore, the 'carer' attitudes and actions of many nurses may indeed hinder shared care. These nurses were only minimally engaged in education for understanding and showed some resistance to shared decision-making and shared care. For the most effective promotion of shared care, nurses should educate broadly and participate in genuine shared decision-making so that patients gain greater understanding of the health implications of dietary, medical and dialysis decisions. Therefore, the drive to increase shared care and hence home dialysis may be more successful if 'carer' nurses are helped to embrace these 'trainer' attitudes and actions when appropriate.

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### CONCLUSION

Policy initiatives to enable patients with chronic illnesses to look after themselves have the potential to empower patients, aid their recovery and make long-term economic sense. Shared care dialysis is a good example of this, with notable successes. However, such initiatives are unlikely to fulfil their potential unless the tension between the 'carer' attitudes and actions of many nurses and their role as trainers can be addressed. With the increasing trend to support self-management by patients with severe long-term conditions, this tension is likely to increase.

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### CONFLICT OF INTEREST

None.

### AUTHOR CONTRIBUTIONS

ID: Principal project leader, conceived and designed study, undertook interviews and analysed data, drafted and approved the final manuscript. SC: Participated in design, coordinated study, undertook interviews and analysed data, helped to draft and approved the final manuscript.

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